

# ENROLLMENT STEPS AND PARTICIPANT INSTRUCTIONS

Thank you for participating in PATH for PWS! The information you share will help us better understand serious medical events in PWS and evaluate how PWS related behaviors change over time. The data from this study are intended to inform the development of new treatments for PWS.

The information below will help you navigate the enrollment process in the Global PWS Registry and PATH for PWS study and completion of the required surveys.

## STEP 1: JOIN THE GLOBAL PWS REGISTRY

*If you aren't already signed up for the Global PWS Registry:*

- **Register** for an account at [www.pwsregistry.org](http://www.pwsregistry.org) using the name of the person who will fill out information (parent or caregiver). Be sure to check your junk email if you don't receive the registry notification
- Under **Participant Enrollment**, add the person with PWS as a participant
- Review the consent information and **Grant Consent**, scrolling to the bottom to check the boxes and [consent to the Global PWS Registry](#)

## STEP 2: ENROLL IN PATH FOR PWS

*After you've joined the Global PWS Registry:*

- **Return to Participant Enrollment**
- Click **More** next to the participant's name under the PATH column and select **View & Grant Consent**
- Review the consent information and **Grant Consent**, scrolling to the bottom to check the boxes and [consent to the PATH for PWS study](#)

## STEP 3: TAKE THE PATH FOR PWS SURVEYS

*Once you're enrolled in the Global PWS Registry and PATH for PWS:*

- **Return to Participant Enrollment**
- Click **Take Surveys**
- Complete the '**Consent for Future Use of De-identified Data**' and the '**Getting Started**' surveys
- Click on the **Initial Surveys** tab to see list of surveys to complete upon study entry
- Complete list of surveys in order listed if possible. Required surveys are marked with an asterisk \*
- **If you are in the U.S.**, consider enrolling in the PATH Blood Test Sub-Study.

➤ **TIP:** The **submit** button is in the bottom right corner when you're finished with a survey. Click **Take Surveys** after each completed one is submitted to get back to the others required.

# ENROLLMENT STEPS AND PARTICIPANT INSTRUCTIONS FOR BLOOD TEST SUB-STUDY

Want to help even more? Join our Blood Test Sub-Study! Some researchers noticed that D-dimer levels, a potential marker of blood clots, are higher in individuals with PWS. PATH participants who live in the U.S. will be asked to consider joining an optional sub-study that involves providing a blood sample at a nearby local lab for analysis of D-dimer. Gift cards are available upon completion of the blood draw.

## STEP 4: ENROLL IN PATH FOR PWS BLOOD TEST

*After you've enrolled in PATH for PWS:*

- **Return to Participant Enrollment**
- Click **More** next to the participant's name under the PATH Blood Test column and select **View & Grant Consent**
- Review the consent information and **Grant Consent**, scrolling to the bottom to check the boxes and [consent to the PATH for PWS Blood Test sub-study](#)

## STEP 5: TAKE THE D-DIMER BLOOD TEST SURVEY

*Once you're enrolled in the PATH for PWS Blood Test sub-study:*

- **Return to Participant Enrollment**
- Click **Take Surveys**
- Complete the 'D-dimer Blood Test' survey with your contact information and consent to allow the study staff to enter the blood test results in the database on your behalf

## STEP 6: GO TO LABCORP FOR THE BLOOD TEST

*After you've received the participant's Lab Order Form and instructions via email*

- Schedule an appointment with LabCorp for the lab draw
- Bring the participant (with the Lab Order Form) to LabCorp for the lab draw